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ABSTRACT

The paper explores ways that families choose a doctor for their child and offers guidelines for physician selection especially for parents with children who have learning disabilities or attention deficit disorders. Results of a survey of parents are reported indicating that parents used an average of only 1.2 sources of information in identifying and evaluating potential doctors. Guidelines for parents are presented as answers to the following questions: What about a child who has a disability? How do you find the right doctor? What do you say to a doctor you have never met? How do you make the first appointment? How do you prepare for your first visit? What do you do when you get to the doctor's office? What should you talk about? How can doctors and schools work together? What are you responsibilities as a parent? How do you evaluate the situation? Special emphasis is placed on the role of the parent as case manager of services for the child, with detailed recordkeeping a part of the parental responsibilty. Four references are included. (DB)

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Choosing a Doctor for Your Child with Learning Disabilities or Attention Deficit Disorders

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How do families choose a pediatrician for their child? Specifically, how do families with a child who may have a learning disability, language delays, or attention deficits choose their pediatrician? How do families work with their pediatrician for the maximum benefit of their child, to locate appropriate specialists, or to correctly assess their child's needs? How do families find "the" pediatrician that can provide the care and support their child needs? These are questions many families ask. This paper will explore these questions and discuss some possible answers.

The first step in obtaining medical assistance for your child must be the identification and selection of a primary health care provider. This sounds simple enough; yet, an article in *Pediatrics*, "First Step in Obtaining Child Health Care: Selecting a Physician," (Hickson, Stewart, Altemeier, & Perrin, 1988) indicates that parents included in the study did not spend much time or energy selecting a doctor. According to its authors, this study is the first to evaluate the process of physician selection for children. The parents were asked how they selected their child's doctor and what factors were important in their decisions. Fifty-three percent of these families considered only two or three physicians in their decision; 34% considered only one. They also indicated that an average of only 1.2 sources of information were used in identifying and evaluating potential doctors. These sources were most commonly talking to a neighbor or friend (44%) and discussing choices with another doctor (21%). The characteristics of the doctor considered in these decisions were primarily communication skills (willingness to share decision making, warmth, concern), then accessibility (return calls quickly, quick appointments), and then quality of practice as determined by recommendations from friends and family.

Parents surveyed in this study were also asked why their families changed pediatricians. The most frequently stated reason for changing doctors was the family's perception that the doctor was not managing a specific illness adequately. The second most frequently stated reason was that parents believed their child's doctor or office staff was rude or unconcerned. Third was that they objected to their physician's lack of interest in their child's behavior. The fact that more than 40% of parents who were dissatisfied with pediatricians expressed this complaint reinforces the notion that parents are concerned about psychosocial health or that perhaps psychosocial health is not addressed adequately in our health care system.

What about the child who has a disability?

All families have unique needs; however, it is very important to the continued progress of the child, that families with a child who is very active, learning disabled, or experiencing any kind of developmental or behavioral difficulties use care and thought in selecting a physician. The number of parents who were dissatisfied with their pediatrician's lack of interest in their child's behavior, coupled with parents who believed their child's doctor or her office staff was insensitive or unconcerned, substantiate the need for extra thought and planning.

Relating to a child or adolescent whose social and communication skills are distinct or unaccommodating is difficult. Yet, a child needs to be able to talk to his doctor as well as develop trust and rapport with her. In addition, the child should be comfortable with his medical needs and care. Even young children need to be able to talk with their doctor. Older children and teenagers need to have more control over their medical decisions and concerns, and need to feel comfortable talking openly with a physician who understands them. Therefore, it is imperative that the doctor you have selected manage a two-way communication with the child, accept the child's unique behaviors, look past such impediments, and treat the child with the same concern shown for other children.

For parents, the primary health care provider serves two major functions. This general practitioner or family doctor oftentimes is the professional parents turn to first when they are concerned about their child's health or development. This physician must treat the whole child and provide a source of trust and expertise in emergencies and medical crises. Secondly,

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this physician can help families coordinate their child's health care by referring them to specialists and clinics, by obtaining developmental and psychological evaluations, and by helping to interpret the results of these tests. Again, this can only be accomplished if the parents are comfortable with the physician and feel she is understanding of their unique concerns and accepting of their child.

How do you find such a person?

Clearly, families with a special needs child will have a greater task before them in the doctor selection process than other families. While the Hickson et al. survey indicates that most families spend little energy choosing a physician, it is none-the-less an important matter which must be approached in a concerned and methodical manner.

As with all selection processes, the first step is to identify your needs. The following questions may help you pinpoint those needs. What is important to your family in dealing with medical needs? What do you expect? What do you think you need? In what ways are your child's needs different from other children's needs, that is, specifically how is your child unique? Do you need several doctors, and therefore, need each to be open to discussions with the others? Do you need a doctor more frequently than most families and want someone close to home? Does your child have more complex medical needs than other children or are his needs related to his development and behavior? Is your child difficult to talk to and does he require more time, for whatever reason, than other children? Do you need more time to discuss your concerns about this child with the doctor?

If your child is significantly different from your neighbor's children, your neighbor's pediatrician may not be the best choice for your child. When seeking personal recommendations for a doctor for your child with disabilities, you may find it beneficial to talk to families whose children are more like your own. Such families may be found at meetings of parents' groups such as the Association for Children and Adults with Learning Disabilities (ACLD) or at a school. Perhaps your child is still very young and you don't know other families in your area with children like yours. Families can find a lot of information in the phone book by contacting doctors listed as Developmental Pediatricians. If there are no such listings, contact a Pediatric Neurologist or Child Psychiatrist, or call the Department of Pediatrics at the closest University Hospital.

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If shopping around for a doctor is not a possibility or if you live in a community with only one or two pediatricians, you will need to develop a relationship with the doctors available to you. There are techniques for communicating effectively with your child's doctor, no matter how she was chosen.

One consideration, should you feel uncomfortable with the local physician, is to establish a liaison with a developmental pediatrician at the University Affiliated Program at the state university's medical school or another major medical center. This pediatrician could then provide tertiary (or secondary) care to your child while coordinating her efforts with the local physician's role of primary health care provider.

When asking for a referral to a local pediatrician, several important steps should be taken. Be sure to request a referral rather than a recommendation. It is difficult, if not impossible, for someone on the phone to recommend a doctor to someone she has never met. A referral is less formal and will net better results. Ask for several referrals, if possible, to allow you some choices and to place less responsibility on the person making the suggestions. You can say, "I have a child ___ years old who may have an attention deficit disorder and/or hyperactivity. Do you see such children in your practice? Is this an area of interest for you? If not, can you refer me to a pediatrician whose special interest is children with developmental difficulties and/or attention deficit disorders?" Ask who is on call when this doctor is not available and does the backup doctor share this doctor's views. Be specific about your child's needs; if he has a severe learning disability or if his behavior is very difficult, be honest about this. After all, you are looking for a doctor who is accepting and comfortable with such conditions.

When you have your list of referrals, begin the process of "interviewing" prospective doctors. Talking to doctors about their areas of interest is not uncommon; there is no reason to feel uncomfortable about such a process. How could you begin? Begin by phoning the physician's office. Ask to speak to the nurse first and ask again if this doctor sees children like yours in her practice. If the answer is yes, or if the nurse seems positive about the doctor's interest in children like yours, ask for the doctor to return your call. Doctors usually set aside some time each day to return calls. Be sure to make it clear that this call will take a bit longer than most and that you would like

her to phone you when there is time to talk for 5 or 10 minutes. Do this for each of the doctors on your referral list.

What do you say to a doctor you have never met?

When the doctor calls, again explain your child's unique needs and your family's expectations. Ask if she is interested in working with the challenges your child will present. Ask the most important questions on your list of expectations for a pediatrician for your child. Does she have experience with children who have social or behavior difficulties? Is she willing to make time available to speak to parents alone? Does she feel comfortable working in a team type situation with other specialists, the family, and school personnel? Can she schedule extra long appointments for children who may require more time?

How do you make the first appointment?

After you have asked these questions to all the doctors on your list, you may want to make an appointment to see the doctor whose responses were most positive and favorable. You will be the one who makes this judgment based on your wants and her responses and general attitude to your questions and needs. You may want to ask if it would be possible to first go alone to talk with her and inquire about the cost of such a consultation. If you would like to first bring your child in for the doctor to examine, then ask if it is possible to arrange an appointment longer than usual. If your child has difficulty waiting and does not do well sitting in a doctor's office, schedule your visit as either the first appointment in the morning or as the first appointment after lunch. Appointments are made with the receptionist or secretary, not the doctor, so be sure to let the receptionist know that your child will not be able to wait comfortably (or you will be uncomfortable controlling your child in a waiting room) and you will take the next available appointment which can guarantee little or no waiting, even if that means setting the appointment weeks in advance. Your stress level is important too, if you do not want to deal with an active child in a crowded doctor's office, then plan your visits in advance and avoid distressing situations.

The more the doctor knows about your child, the better able she is to discuss your concerns.

How do you prepare for your first visit?

This new doctor will need information about your child and his medical history. Before the first appointment, be sure all medical records are either mailed or delivered to the doctor's office. It would be useful for these records to arrive at least a week before your visit so that the doctor has time to review them.

If your child has already been seen by specialists, have these reports sent to the "new" doctor also. If your child has had educational assessments, send these along as well. The more the doctor knows about your child, the better able she is to discuss your concerns. A word of caution about records: try to keep the volume of information manageable. After all, the doctor cannot spend hours reading your child's reports, so try to send summaries and results rather than the full report.

Requesting that medical records be sent to another doctor is routine and you should

not feel uncomfortable requesting this. If your child has already been seeing a doctor, it is acceptable to request an additional opinion without insulting the first doctor. You can phone, or write, the first doctor's office and say, "I am interested in discussing my child's situation with another doctor to get additional opinions. Please send a copy of my child's records to Dr. (fill in the name) at (give the mailing address)."

It would save time and you would be assured of neglecting nothing if you made a list of topics for discussion with the "new" doctor. Since many children are shy around a doctor, especially one they've never met before, you may need to discuss problems which the doctor cannot readily see. For instance, if you suspect your child may have a language delay, say so. Then the doctor can try to initiate more conversation from your child to better observe your concerns. If you are worried about possible developmental delays, make a list of things your child does or does not do. This gives the doctor concrete examples of behavior she may not be able to observe in the office. If you would like a referral for a hearing screening or vision test, be sure to mention this. The doctor may conduct preliminary visual, hearing and speech screenings in her office to determine if a specialist is needed.

What do you do when you get to the doctor's office?

Look around. Is this office "child proof?" Are toys available to your child? Are there many things he should not touch or climb? Can you let your child move around in this office without undue restraint? Is the bathroom conveniently located?

How are the office staff? Do they seem open and friendly, or do you feel out of place here? Are the nurses who weigh your child, conduct eye exams, and perform some of the examination functions comfortable with your child? Are they pleasant to you and your child and supportive of your needs?

Does your child seem comfortable, or at least as comfortable as any child feels, in

the doctor's office? If he is frightened, is the staff warm and reassuring?

After the doctor has examined your child, you might ask if the nurse or receptionist could take him out of the room for a few minutes so you can talk to the doctor alone. Children who are very active can make conversation difficult for both you and the doctor. If this is not possible, ask if the doctor can phone you later in the day to discuss your child and pick a time when you can talk on the phone uninterrupted.

What should you talk about?

Remember that many doctors may not have had formal training or experience in learning disabilities, attention deficit disorders, or family stress. You may need to do a bit of teaching yourself and explain your situation as precisely as possible. When doing this, try to be as unemotional as possible; professionals will discuss matters with parents who seem in control of the situation more easily than with parents who get overly emotional.

It may be useful to be more thorough than making out a list of topics. You may want to develop a list of questions. In this way, you will not waste each other's time and will not forget any of the points about which you wanted to ask.

If you have a child who is having some difficulties in school, and you want to discuss this concern, remember this may be another area that is unfamiliar to many doctors. Just as you are uncomfortable with doctors who use medical terms you do not clearly understand, doctors can be uncomfortable with education jargon. Explain your child's educational needs and placement clearly. Doctors can make specific recommendations to schools, so talk about concerns you have with your child's education. Therapies, such as speech therapy or physical therapy, can be recommended by the pediatrician. Referrals to other specialists may also be in order. Perhaps the school nurse would like the opportunity to talk to the doctor; ask if that would be possible.

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If you just want time to talk over your concerns for your child's overall development, say so and arrange for a time when both you and the doctor can discuss your questions at leisure. It may be a good idea to arrange a time when both parents, or primary care givers, can get together. If you state your needs clearly, then the doctor is better able to arrange appointments which will best serve your needs. If you don't ask, you certainly won't get.

How can doctors and schools work together?

While children with learning disabilities may have no more medical needs than other children, processing problems and other learning problems can sometimes be linked to sensory conditions which interfere with school functioning. Medical conditions such as meningitis, head trauma, or serious ear infections can put a child at risk of learning disabilities. You may find these issues important to discuss. In doing so, you may wish to work towards establishing a relationship between the doctor and school. You can help develop this sort of relationship by sharing school report cards, therapy arrangements, evaluations, and conference reports with your child's doctor. It may also be useful to share ideas for learning and/or behavior control or modification that have worked. The more the doctor knows about your child and other children with similar difficulties, the better able she is to help.

In the same way, share the doctor's suggestions with school staff. Let the school know any medical information which may be important to them, certainly any changes in medication or medical conditions. If a child is recovering from an illness or has special health care needs, including stress, discuss this with the school staff as well as the doctor. You are working on team building, and all team members need to be kept informed and up-to-date. Some medical conditions can be related to school stress, such as frequent stomachaches, headaches, or skin irritations. Such anxiety-related conditions may require changes in school programs or expectations. Sometimes, difficulty in school can lead to psychosomatic complaints which both the doctor and the school staff need to be aware of and discuss.

What are your responsibilities as a parent?

Parents also have medical responsibilities. You, after all, are the ones who will carry out the doctor's recommendations. You are the primary care giver of your child, and to do so, you need to be sure you understand the doctor's advice.

Take a notebook with you so you can write down any instructions. If the doctor prescribes a medication, be sure you understand its purpose, how it is to be given, and when. Should it be taken before, after, or during meals? Does four times a day mean you need to give the child medicine at midnight or do you just divide the daytime hours? Does the medication have to be given at school or can the medication be delayed an hour until your child comes home? Are there side effects? Can you stop the medication when the child seems better, or does he need to finish all that is in the bottle? Are there interactions with other commonly given medications which could be dangerous?

If the doctor refers you to a specialist or requests tests be done, ask how this test or referral will make a difference in the treatment of your child. What information is needed to help this child and how will this referral supply that? Ask the doctor to help coordinate this referral and/or tests so they will be conducted efficiently and will cause as little trauma for your child as possible. For instance, if blood tests are necessary, can they all be done at one place so blood will only need to be drawn one time? The object is to get the maximum information with minimum discomfort to your child. Even if several phone calls need to be made or you need to wait an extra week or drive an extra ten miles, the decision should be based on what's most beneficial for your child.

Remember that it is often difficult for a pediatrician to say "I don't know." You should ask all the questions you need so that you understand all recommendations and diagnoses. You need to also be aware, however, that not all your questions can be answered. While parents are anxious about their child, a period of observation may be the best plan. Also, remember that change takes time. In a team effort, everyone needs to take his turn listening and understanding.

How do you evaluate the situation?

Evaluating the situation is an ongoing process involving team effort. Families see their child most, then schools (if the child is school age); while a doctor sees the child infrequently. Therefore, families are the primary evaluators of their child's progress. Children frequently behave differently in school and at home. It is important for everyone to communicate openly. Teachers and therapists report regularly; if you feel you need more information from school, you can arrange to meet with your child's teacher(s) and/or therapist(s) to discuss your concerns. Information from the family/school team can then be presented to the doctor, if appropriate, and she can join the team for some decisions or suggestions. Since the doctor is the only team member who has no opportunity to observe your child "in action," you must report all relevant information accurately.

Evaluation of the doctor herself is a parent responsibility. With the list of needs discussed at the beginning of this article, you can develop your own criteria of satisfaction. Establishing a good partnership with your child's doctor is the overall goal. This will take some time on both parts. You and your child's doctor should have mutual understanding of needs, schedules, perceptions of emergencies and non-emergencies, etc. It is usually worthwhile to work on your relationship with your child's doctor and to change doctors only if you feel that she is unresponsive to your concerns or if you are uncomfortable with the doctor's responses to your child.

To summarize...

Your child may be seen by several doctors, clinics, and hospitals. Ultimately, you—his parents—are the case managers of your child's services. Your case manager duties are likely to include choosing a pediatrician, developing a relationship with her, evaluating the situation, and maintaining any records that result from the visits.

You are the primary care giver of your child, and to do so, you need to be sure you understand the doctor's advice.

Detailed record keeping is a vital part of your responsibilities. While doctors maintain files for their records, you should maintain files also. Your home files could be as simple or sophisticated as you choose to develop. Most importantly, good communication and rapport among your child's team—you, your child if appropriate, primary health care provider, school personnel—should lead to quality care for your child with learning disabilities.

Much of the information for this paper was taken from an interview with Dr. Karen Miller, a developmental pediatrician whose practice includes children with attention deficit disorders. Dr. William Goldman, who practices pediatrics in Arlington, Virginia, reviewed this paper.

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